



UNIVERSITY OF
BIRMINGHAM



Is Building the Right Support working?

What we found out about better
community services for people
with a learning disability or autism.

November 2019



Easyread version

About this paper



This paper is about good support in the community. It talks about support for people with a learning disability or autism whose behaviour challenges services. And their families and carers. Many people live in hospitals because they cannot get the right support closer to home.



Transforming Care Partnerships (TCP) plan how to help people move out of hospital. But first they need to have the right support in the community. The job of TCPs is to make local support better so that people do not have to go into hospital. TCPs include people from local health, social care and providers.



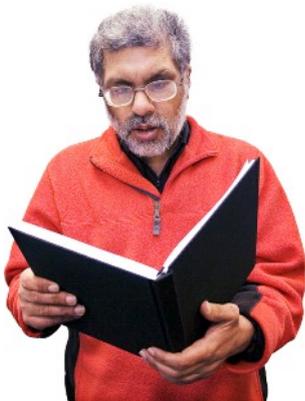
Building the Right Support is a national plan to help **commissioners** plan better community services. The NHS Long Term Plan is using these ideas to help plan services and support in the community. This support will help people move out of hospitals and live more independently.



In December 2016, NHS England chose The Strategy Unit, ICF, the University of Birmingham, and BILD (The British Institute of Learning Disabilities) to find out what is working and what can be done better. This team of researchers wrote this paper.



Between December 2016 and March 2019 we looked at what makes good community support and what could be better.



This paper has been written to show people and families what we found out.

This paper is about what we found out from:



- **Transforming Care Partnerships**



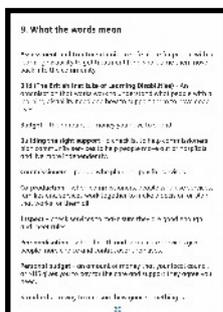
- people with a learning disability or autism



- families and carers



- managers and people who work in services.



Some words are in **bold**. There is a list of what they mean at the end of this paper.

1. Working together to give good support

What we found out

Community support is getting better. But **commissioners** must:



- have services for adults and children who have lots of different needs. And the right services for adults and children with autism



- think about other services that could fill gaps in community care. For example, help people stay out of trouble or use the same services and support as other people



- learn about working together from **Transforming Care Partnerships** that are **commissioning** better services.

Our ideas for the future



- **commissioners** should have the skills to help people plan the housing and support they choose. This includes working with other organisations to plan for the future



- plans for health and social care services should give people more choice and control all through their lives. This includes family carers



- people should have the right to a **personal budget** for both health and social care if they want it. They control this money to have support to live the life they choose



- work with people and their families to decide national **standards** for good **commissioning**



- make sure **commissioners** have the right skills to work in this way.

2. Having the right staff in the community

What we found out



It has been difficult to get the right staff. We still need:

- more staff in the community who know how to support people with lots of different needs



- services that everyone uses that support people with learning disabilities in person-centred ways



- good support for staff who work with people whose behaviour challenges services. So they can support people and their families better. This includes making sure staff are paid more because of their skills and experience



- to understand that family carers are as important as paid workers.



Our ideas for the future

- have national and local plans for health and social care workers. This must include training for family carers



- good support for social care staff. Including the chance to move on and do well in their job



- understand the skills staff need to support people with a learning disability and autism and their families. Know it is important to keep spending money on training for staff



- training about autism for all NHS and social care staff.

3. Support for children and young people

What we found out

Support for children and young people is as important as support for adults:



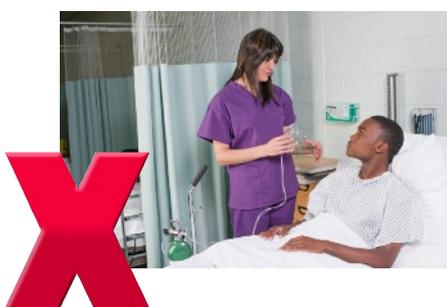
- services for children and adults must work together to support children, schools and families before things go wrong



- services must give children and young people the support they need and more choice and control



- schools and colleges should make changes so children and young people with a learning disability have the same chance to learn as other children



- special community support teams can stop children and young people being in hospital for a long time.

Our ideas for the future



- support children and young people as early as possible



- have education, health and social care services that work together really well



- make sure schools and families get support from special community teams



- find ways to support children closer to home when they have lots of different needs. A keyworker could make sure they get this support in their community



- have better information about what services people will need in the future.

4. Places to live

What we found out



It is important to have the right places for people and their families to live. But this can be very difficult:

- many **commissioners** do not know how to plan the homes people need. They also need to meet rules about keeping people safe
- **commissioners** should have support from housing advisers. They help them plan and pay for housing people and their families need
- **Transforming Care Partnerships** now understand how to link their housing plans to what people need.



Our ideas for the future



- spend more money on the types of housing people and their families want and need



- local councils and the NHS work together to plan the homes people need



- have places where people can go instead of hospital in an emergency.

5. Money

What we found out

The money to pay for a person's care should go with them when they move from hospital to the community. But this can be difficult because:



- it can cost more when someone first leaves hospital. Some areas can see the cost goes down over time



- in some areas health and social care services work together to plan and pay for community services from the same **budget**.

Our ideas for the future



- people get better community support when NHS and social care services work together and put their money together



- the **budget** for your care should stay the same if you leave an **assessment and treatment unit** after more than a year



- we need to understand more about what happens over a longer time if people have community support instead of living in hospital. What does it cost? Is it better for people?

6. Personalisation



What we found out

After a while **commissioners** and services were better at giving people more choice and control.



But most areas do not have an organised way to tell people about having their own money to plan their health, care and support.



Our ideas for the future

Local areas must concentrate on personalisation and make sure people know they have a right to choose their support.

7. Planning with people and families

What we found out



- most areas are getting better at **co-production** (planning with people and families)



- different areas are working in different ways. It is best when people have the time and support they need. **Building the Right Support** says how to do this



- **commissioners** think working with people and their families helps them make better decisions.

Our ideas for the future



- areas must keep working on **co-production** and spend time to get it right. This includes giving people control over what we talk about and when



- it is important to listen to include ideas from people and their families when services are **inspected**



- people and their families must be involved in checking and planning services.

8. What the government should do next

NHS
England



These are our ideas for what should happen next:

- NHS England should write an action plan using these ideas



- the government should publish its plan for changes to social care and ways to pay for health and social care by 2020



- different parts of the government should work together better. They need plans for things like making changes so children with a learning disability and autism have the right support



- health and social care services should work together to make sure people with a learning disability and autism get their rights



- do more work to find out whether better community services save money for education, health and social care over time



- keep making sure local councils and social care services are involved as well as the NHS



- make sure everyone understands it is important for people to move from hospitals to live in the community.

9. What the words mean

Assessment and treatment unit - a safe place for people with a learning disability to get treatment for a short time then move back into the community.

Bild (The British Institute of Learning Disabilities) - An organisation that works to understand what people with a learning disability need and how to support them to have good lives.

Budget – the amount of money you have to spend.

Building the right support - a checklist to help commissioners plan community services to help people move out of hospitals and live more independently.

Commissioners – people who plan and pay for services.

Co-production – when commissioners, people who use services, families and services work together to make a decision or plan that works for them all.

ICF - is an independent research organisation that helps services work better.

Inspect – check services to make sure they are good enough and meet rules.

Personalisation – when health and social care services give people more choice and control over their lives.

Personal budget - an amount of money that your local council or NHS gives you to pay for the care and support they agree you need.

Standards – a way to measure how good something is.

The Strategy Unit - are independent researchers who are part of the NHS and who help commissioners and services to plan and make services better.

The University of Birmingham - are experts in research on health and social care.

Transforming Care Partnerships – local NHS and councils who plan to help people move out of hospital and have the right support in the community.



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